



House Health and Government Operations Committee

March 9, 2022

HB 1020: Developmental Disabilities Administration – Self-Directed Services

Letter of Information

The Arc Maryland and People on the Go of Maryland are two state-wide advocacy organizations dedicated to the rights and quality of life of and for people with intellectual and/or developmental disabilities. There are currently close to 2000 individuals supported in DDA HCBS Waivers who self-direct their services and support. This means that people with disabilities, with support from their families and others if needed, take responsibility for managing their services, including hiring and supervising the people who provide their direct support.

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland by and for people with intellectual and developmental disabilities.

This bill has been brought before the general assembly twice previously, but this bill version comes after a summer-long workgroup, where stakeholders, DDA, and members of the House and Senate came together to try to work through some of the issues and develop solutions. While much work was done this session, and recommendations were made, the workgroup did not have time to work through how certain recommendations could be operationalized to effectively protect the federal match of Medicaid funding upon which the state relies, and to fully meet the intentions of the advocates.

We believe that people with disabilities should be empowered and supported to self-direct their services and to **receive assistance to do so from people they choose, hire, and trust, including family members** with protections built into their plans to address any conflicts of interest.

Self-Directed service options should be designed with **cost-neutrality** in mind compared to traditional service costs and should be flexible to meet the needs of the individual to meaningfully live, learn, work, play, and worship as the person chooses.

While The Arc Maryland and People on the Go (POG) agree with several bill components detailed below and the need to codify certain definitions to restore services and supports to the self-directing participant, there are a couple of changes the bill proposes about which we have concerns. We believe that unintended consequences may come from codifying some of the suggested changes to the program. These are described below.

First: some background on Self-Directed Services.

In 2005, the state of Maryland worked with people with IDD, families, and other advocates to create a waiver pilot program under which individuals with intellectual and developmental disabilities self-directed the funding they received from the Developmental Disabilities Administration (DDA) for their needed supports. The program was called “New Directions,” and it allowed people to hire their own staff and make decisions regarding where and how their funding

would be used to access service options they needed. By allowing people with IDD to make funding decisions about services and supports, it gave them more choice and control over what services they received. The belief was that as a result, funds would be spent more effectively and efficiently. **What started as the “New Directions” waiver, became the DDA self-directed services option available through the Community Pathways, Community Supports, and the Family Supports Medicaid waivers in Maryland.**

Over time, the self-directed service model has remained a wonderful service model for many with IDD, however through waiver amendments, the service definitions and the structure of the program changed significantly over time without clear reasons for some of the deep changes.

We agree with the components of this bill to:

- 1. Restore family as staff (with safeguards).**
- 2. Restore Awake Overnight as a service that can be self-directed.**
- 3. Restore more hours and duties to the Support Broker service option.* (with caveat)**
- 4. Ensure CCS provide accurate and complete information to individuals on both the traditional service and self-direction service options.**
- 5. Ensure people do not have to undergo a competency test to self-direct.**
- 6. Expand Individual and Family Directed Goods and Services to allow for people to have more than \$5500 available to access services for which they have an assessed need.* (with caveat)**
- 7. Provide Transportation as a reimbursable service. Do not consider funding for transportation is adequately “included” in the rate.**

Justifications for these changes:

- Family, who are not legally responsible for a person, used to be able to be hired by the self-directing person as staff. Family members who serve as staff for a person under self-direction, often do not work another job. Working for their loved one is their job and many times it works out well for the individual to be able to hire a person who knows them best. This option to hire certain family members was initially curtailed through a waiver amendment and then finally restored after a couple of years of stakeholder feedback. **It is important that the person still makes this choice, and that certain oversight and safeguards are in place.**
- Awake overnight supports were cut in one of the waiver amendments despite significant stakeholder feedback this change would create a serious disruption in the lives of many. After approximately 3 years of advocacy, the current Secretary of Health, Dennis Schrader announced last week that DDA would be restoring the service with the next waiver amendment. **People with IDD should be able to self-direct awake overnight supports if they have an assessed need for overnight support to address behavioral or medical need. Personal Supports should not be capped at 82 hours** as it is in the current waiver: people who need awake overnight support may need up to 56 hours more of Personal Support Services.
- Support Broker hours and allowable duties were capped and curtailed in one of the waiver amendments. Service hours may now be only 4 hours per month, even though DDA previously estimated people needed an average of 11 hours of support broker assistance per month (see 2013 waiver amendment) and stakeholder feedback to the waiver that this would be highly disruptive to a person’s life. The service has not been restored and Coordinators of Community Services (CCS) generally do not have the capacity to take on the additional duties and time commitments for people with IDD on their caseloads. ***While**

we agree that the service should not be capped at 4 hours per month, we do not agree with the arbitrary service cap at 40 hours per month in this bill as it is not rooted in data. The number of hours a person needs should be discussed and agreed to by the individual and their team and reviewed for appropriateness by DDA. There should also be requirements to ensure there is not an overlap of service at any given time between a support broker and a CCS to avoid duplications of duties.

We agree with the bill intention that **support broker “allowed” duties should be written more expansively** as they once were under New Directions, again- with a clarification that the duties and hours may not overlap with CCS hours for the same service.

- **Coordinators of Community Services (CCS) should be trained sufficiently on service definitions and what is possible under both traditional and SDS models so individuals are making informed choices.** Individuals and their families should receive reliable and accurate information about how each model operates, the service definitions under each model, and the responsibilities and requirements of participation in each model.
- **Everyone can self-direct. A person should not have to undergo a competency assessment to prove ability to self-direct.** The RFP for a new Financial Management Service (FMS) initially indicated that the service would include competency testing for individuals in the program. The stakeholders protested and the requirement was removed from the RFP, but then the Designated Representative Form, that the advocates had been working on with DDA for several months, was suddenly reworded to require a person to relinquish their rights in certain areas if they were to assign a “designated representative” to help them. Again, the stakeholders protested, and eventually, the form was reworded to clarify that people may assign supporters to assist them with certain aspects of their plans, but do not have to give up any rights to do so.
- **The list of individual and family directed goods and services should be expanded to other services and supports allowed by CMS for federal match,** and DDA should work with stakeholders to examine the cap which currently restricts an individual’s ability to access what they need over \$5,000.

***We do not agree that the funding available in this category be up to the total dollar amount of the individual’s un-utilized annual budget plan.** We support equity between both traditional and self-direction service models, and this would increase the funding for a service that already is unavailable to people in the traditional service model. DDA funding is limited, and we want to support as many people with IDD in the state as the DDA annual budget and quality will allow, not open up “catch-all” pots of funding for people to spend un-utilized amounts of their planned budgets. If this was allowed through Self Direction and extended to traditional services, we believe the effect would have consequences for people on the waiting lists for services.

- **Transportation for people who self-direct should not be included in “wages” to a staff person but should be paid as a reimbursement to staff based on IRS standards.** Currently, transportation for people who self-direct is considered “included in the rate” they receive for the service. This is a problem for people who self-direct as well as a concern of traditional providers as it disproportionately impacts people who live in rural areas or transportation deserts, and especially people who need more expensive transportation (lift vans and paratransit). For these individuals, the rate is not sufficient to cover transportation. In addition, the rate paid to the staff in self-direction through wages is taxed

which does not make sense for the employee as they are getting reimbursed for mileage, and this reimbursement should not be taxed.

While some of the changes made by DDA and Maryland Medicaid to the waiver were necessary to improve oversight, some of these changes do not appear to be rooted in data or needed for appropriate oversight, or with consideration for the strain it would cause people in the program and their families.

In the past few years, some of the services and requirements have been restored and changed in response to significant feedback, and especially through the leadership of the current Secretary of Health, such as allowing family members to work as staff, not requiring competency testing, and recently- committing to restore awake overnight as a service that can be self-directed.

While we are grateful and appreciate the commitments and changes that have been made, there is no guarantee that the next Secretary will maintain the changes, and no guarantee that there won't be additional changes to key components of the program.

The Arc and POG **do not support** the following changes this bill would establish:

We do not support the proposed **amendment to §7-409(A)(6)**. The proposed amendment would allow a self-directing participant to hire someone to help manage the person's "home, staff, and other administrative duties." If the general assembly restores support broker duties and expands the allowable hours for support brokerage through another section of the bill, we believe the administrative support a person needs will be addressed without this additional amendment. We have concerns that the administrative role that the Sponsor is trying to create through amendment would not be eligible for federal matching funds **and** may be a duplication of what a support broker or a CCS would do.

We also do not support:

(C) THE ADMINISTRATION MAY NOT ESTABLISH A LIMIT ON:

(1) THE DOLLAR AMOUNT OF INDIVIDUAL-DIRECTED FAMILY GOODS AND SERVICES PROVIDED TO A RECIPIENT; OR

(2) THE NUMBER OF HOURS OF OVERNIGHT SUPPORTS PROVIDED TO A RECIPIENT WHO RECEIVES SELF-DIRECTED SERVICES.

DDA and the state should maintain the ability to make certain changes to waiver services and establish limits **however we would support that future changes should be based on measurable and transparent data, and truly incorporate stakeholder feedback provided.**

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